

Virginia Genetics Advisory Committee

Tuesday, October 5, 2004

10:00 a.m. – 12 p.m.

Division of Consolidated Laboratory Services (DCLS)

Room T-23

600 North 5th Street

Richmond, VA 23219

Telephone (804) 648-4480

MINUTES

Present: **Willie C. Andrews**—DCLS; **Lynette Bartlett**, LPN—VDH; **Joann N. Bodurtha**, MD, MPH, Chair—VCU; **Mary Ann Discenza**—DMHMRSAS; **Laura Duncan**, MPH, RD—VCU; **Nancy Ford**, MPH, RN—VDH; **Sara Long**—March of Dimes Va. Chapter; **James (“Jim”) L. Pearson**, DrPH—DCLS; Virginia (“Ginny”) K. Proud, MD—CHKD; **Allison Schreiber**, MS—VCU/VDH; **Jene O. Radcliffe-Shipman**—VDH; **Charlie Stevenson**, MS—DCLS; **Sharon Williams**, MS, RN—VDH; **William (“Bill”) G. Wilson**, MD—UVA Health Sciences Center; **Melody Persinger Yeargin**—CHKD

Guests: **Sarah Elsea**, PhD—VCU; **Vicky Morrell**, Parent; **Jana Monaco**, Parent, Member of VaGAC Community Partnerships Subcommittee, Parent Involvement Work Group; **Karina Seidel**, VCU Genetic Counseling Student

Absent: **Joanne S. Boise**, MSPH—VDH; **Nancy Bullock**, RN, MPH—VD; **Anil Kumar**, MD, VCU; **Joan Corder-Mabe**, RNC, MS, OGNP—VDH; **Kathleen M. Link**, MD—Inova Fairfax and Fairoaks Hospitals; **Walter Nance**, MD, PhD—Va. Newborn Hearing Screening Cmt; **Arti Pandya**, MD, MBA—VCU; **Ether Richardson**, LPN—VDH; **Gwen Smith**, RN, MSN—VDOE; **Harvey Stern**, MD, PhD—Genetics and IVF Institute; **David Suttle**, MD—VDH

Item	Person	Notes/Plan
1. Welcome A. Introductions B. Approval of 04/05/04 Minutes. C. Review of Agenda D. Membership List	A. J. Bodurtha B. J. Bodurtha C. J. Bodurtha D. N. Ford	A. Members introduced themselves to the committee. B. Approved as written. Note: Final minutes are posted on VDH Minutes Calendar Web page http://www.vdh.state.va.us/minutes/minutes.asp C. Order of the agenda changed. D. Circulated and updated by members.
2. Update: House Joint Resolution 164. Infant screening program for metabolic disorders; Joint Commission on Health Care to collect data.	N. Ford	The 2004 General Assembly passed HR 164 to collect information on Virginia Newborn Screening Services (VNSS). VDH currently screens for 9 disorders. The Joint Commission on Health Care (JCHC) requested VaGAC position on the general concept of expanding VNSS panel to incorporate the recommendations of the study released by the American College of Medical Genetics, as requested by the HRSA Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children (HRSA Adv. Cmt.). For more information, see http://www.mchb.hrsa.gov/programs/genetics/committee/ Plan: <ul style="list-style-type: none">• W. Andrews will convene NS Subcmt. after VaGAC meeting to compose response to JCHC memorandum.

<p>3. The Consequences of Newborn Screening- Good and Bad, and Bringing Virginia's Newborn Screening Services to the 21st Century</p>	<p>J. Monaco</p>	<p>J. Monaco spoke on the topic of newborn screening. The purpose of her presentation was "to share the harsh reality of undetected inborn errors of metabolism and why it is necessary to bring Virginia's newborn screening program to the 21st century." Three years ago, her soon to be 7-year-old son, Stephen, was diagnosed with Isovaleric Acidemia (IVA), which caused severe, global brain damage. IVA is not included in Virginia's panel of newborn screening. A testimony to the significance of early detection is her 2-year-old daughter, Caroline, who was diagnosed with an amniocentesis and is doing well and has normal development. Because of her experience, J. Monaco provided public testimony at the HRSA Adv. Cmt. meetings. J. Monaco provided copies of the HRSA Adv. Cmt. September meeting presentation materials, which were later distributed to VaGAC NS Subcmt. members. J. Monaco's presentation concluded by strongly recommending that Virginia expand its panel of newborn screening disorders to include those recommended by the HRSA Advisory Cmt.</p>
<p>4. Updates: Agencies, Organizations A. VDH: Virginia Genetics Program including Va. Newborn Screening Services B. VDH: Virginia Sickle Cell Awareness Program, including Newborn Screening Follow Up for Sickle Cell Trait Carriers C. Division of Consolidated Laboratory Services D. Va. Congenital Anomalies Tracking and Prevention Improvement Project (VaCATPIP). E. March of Dimes, including Virginia Council on Folic Acid (VCFA), Va. Folic Acid Campaign, and MOD grants. F. Va. Dept. of Mental Health, Mental Retardation, and</p>	<p>A. S. Williams B. J. Shipman, K. Seidel C. W. Andrews D. N. Ford E. J. Bodurtha F. S. Long G. M.A. Discenza H. G. Smith</p>	<p>A. Most complete year of data is 2003 with 99,350 births. B. K. Seidel and J. Shipman are planning a pilot program for trait carriers. C. Brought on MCADD and diagnosed two cases so far. In process of expanding StarLims to entire division in collaboration with other states. Also working on improving the data and quality assurance of system and linking birth records with diagnosis. D. The CDC-funded project entitled "VaCATPIP I" will end February 28, 2004. The VaCATPIP I-supported conference entitled "Genetics Horizons: Integrating Genetics Into Public Health" will be held November 18, 2004. A registration brochure was sent to VaGAC members. VDH is applying for a CDC 5-year grant entitled "Population-Based Birth Defects Surveillance Programs and the Utilization of Surveillance Data by Public Health Programs". The purpose of the proposed project, VaCATPIP II, is two-fold: (1) to facilitate the use of surveillance data by public health programs to prevent birth defects and (2) to transform Virginia's population-based birth defects surveillance system into a model program. A request for support letters from VaGAC members was sent to all members. Plan: <ul style="list-style-type: none"> • <u>VaGAC members</u> will return support letters to VDH by October 12, 2004. E. The VCFA, which is supported by VaCATPIP I, concentrates prevention activities in three major areas: (1) Professional Education, (2) Community Education, and (3) Mass Media. In June 2004, a major mass media campaign was implemented. A public service announcement (purchased 1229 spots) stating the</p>

<p>Substance Abuse Services: Part C of IDEA: Infant & Toddler Connection of Virginia</p> <p>G. Va. Dept. of Education</p>		<p>announcement (purchased 1229 spots) stating the importance of folic acid intake for women of childbearing age was broadcast in health districts with the highest rates of neural tube defects (see June 8, 20004, VDH News Release http://vdhweb/news/PressReleases/2004/060804FolicAcid.asp). This campaign will be replicated for National Folic Acid Awareness Week, January 24 – 30, 2005. With a limited capacity, folic acid supplements have been made available to specific programs and health departments. VCFA members have spoken and distributed folic acid materials to various organizations and programs as well as public and school events (i.e.; health fairs). The annual VCFA meeting will take place on October 22, 2004, and the speaker, Thomas Sadler PhD, will present the topic “Origin and prevention of Birth Defects: Timing is Everything!”</p> <p>F. No report.</p> <p>G. No report.</p>
<p>5. Updates: Virginia Genetic Centers</p> <p>A. Eastern Virginia Medical School</p> <p>B. University of Virginia</p> <p>C. Virginia Commonwealth University</p> <p>D. RFP N. Va.</p>	<p>A. V. Proud</p> <p>B. W. Wilson</p> <p>C. J. Bodurtha</p> <p>D. S. Williams</p>	<p>A. As of March 1, 2004, EVMS was designated as a metabolic follow-up center.</p> <p>B. Struggling with funding issues.</p> <p>C. See items 2 and 7A. Assisting in writing VaCATPIP II grant (see item 4D).</p> <p>D. An emergency extension was received for N. Va. because there were no bids on first request for proposal (RFP)—a second modified RFP was implemented and a contract was completed with GIVF for maternity-only genetic services.</p>
<p>6. VaGAC Infrastructure</p>	<p>J. Bodurtha</p>	<p>Discussed current communication processes (e.g., should subcommittees be required to document minutes and send to all members). No change was made. Subcommittee chairpersons encouraged to recruit more diverse members.</p>
<p>7. Report from VaCATPIP Subcommittees/Work Groups</p> <p>A. Genetics and Public Health Subcommittee, State Genetics Plan Work Group.</p> <p>B. Newborn Screening Subcommittee, Tandem Mass Spectrometry (MS/MS) Work Group</p> <p>C. Community Partnerships Subcommittee,</p>	<p>A. Bodurtha</p> <p>B. W. Andrews</p> <p>C. Schreiber</p> <p>D. S. Williams</p>	<p>A. Finishing up second year of MOD grant. Have done a number of focus groups. Third year plan to do broader focus. Results of year 1-3 reports will be used to develop state plan. J. Bodurtha introduced the need to put together a Genetics /DNA workgroup.</p> <p>B. The booklet <i>Newborn Screening Facts: Questions Provider Frequently Ask About Newborn Screening</i> has been updated, distributed, and published online (http://www.vahealth.org/genetics/Newborn%20Screening%20Facts_404.pdf). A survey was completed on how other states finance newborn screening costs. A letter will be sent to Dr. Sullivan regarding his concern on pediatricians financing follow-up screening tests. In response to the July 2004 letter that was sent to states from Dr. Peter van Dyke, Associate Administrator for Maternal and Child Health, Department of Health & Human</p>

<p>Parent Involvement Work Group</p> <p>D. VDH Contractors Subcmt.</p>		<p>Services—which encourages newborn screening programs to facilitate the development of educational materials that inform parents about the option to have their babies screened for additional disorders—VDH and DCLS are modifying the Virginia Newborn Screening Services (VNSS) parent brochure to include information about the option to have their babies screened for additional conditions that could be routinely tested in the newborn period but at this time are not covered by VNSS and added language to VDH Web site. J. Monaco suggested information should be given out during prenatal period.</p> <p>Plan:</p> <ul style="list-style-type: none"> • W. Andrews will convene NS Subcmt. to follow-up on developing a process for providing information to parents during the prenatal period. <p>C. Two parents have agreed to be members of the Parent Involvement Work Group, and letters were sent to see if additional parents could join.</p> <p>D. There is still a void in Northern Va. for pediatric genetics (VCU & UVA are seeing some of these referrals). Treatment (i.e., special formulas and food products) of metabolic disorders for infants in medically indigent families and pregnant women is essentially an unfunded mandate. House Bill 1216, which was continued to 2005 in Commerce and Labor, if passed, would required health insurers, health care subscription plans, and health maintenance organization to provide coverage for metabolic treatment formulas (http://leg1.state.va.us/cgi-bin/legp504.exe?ses=041&typ=bil&val=hb1216&Submit=Go).</p> <p>Plan:</p> <ul style="list-style-type: none"> • S. Williams will schedule a Contractors Subcmt audio-conference to review revised reporting form.
8. New Business	All	None
<p>9. Next Meetings</p> <p>A. VaGAC Meeting</p> <p>B. VaGAC Steering Committee</p>	J. Bodurtha	<p>A. VaGAC Meeting:</p> <ul style="list-style-type: none"> • Date: Tuesday, March 29, 2005 • Time: 10 a.m. – 12 noon • Location: Division of Consolidated Laboratories <p>B. VaGAC Steering Committee Conference Call:</p> <ul style="list-style-type: none"> • Date: Tuesday, February 24, 2005 • Time: 3 – 4 p.m. • Call-in number: N. Ford will arrange conference call and send information to Steering Committee.
10. Adjourn	J. Bodurtha	Meeting adjourned at 12:00 p.m.